

Paradoxes in Advance Care Planning: The Complex Relationship of Oncology Patients, Their Physicians, and Advance Medical Directives

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A B S T R A C T

Purpose

Many seriously ill patients with cancer do not discuss prognosis or advance directives (ADs), which may lead to inappropriate and/or unwanted aggressive care at the end of life. Ten years ago, patients with cancer said they would not like to discuss ADs with their oncologist but would be willing to discuss them with an admitting physician. We assessed whether this point of view still held.

Patients and Methods

Semi-structured interviews were conducted with 75 consecutively admitted patients with cancer in the cancer inpatient service.

Results

Of those enrolled, 41% (31 of 75) had an AD. Nearly all (87%, 65 of 75) thought it acceptable to discuss ADs with the admitting physician with whom they had no prior relationship, and 95% (62 of 65) thought that discussing AD issues was very or somewhat important. Only 7% (5 of 75) had discussed ADs with their oncologist, and only 23% (16 of 70) would like to discuss ADs with their oncologist. When specifically asked which physician they would choose, 48% (36 of 75) of patients would prefer their oncologist, and 35% (26 of 75) would prefer their primary care physician.

Conclusion

Fewer than half of seriously ill patients with cancer admitted to an oncology service have an AD. Only 23% (16 of 70) would like to discuss their ADs with their oncologist but nearly all supported a policy of discussing ADs with their admitting physician. However, fully 48% (36 of 75) actually preferred to discuss advance directives with their oncologist if AD discussion was necessary. We must educate patients on why communicating their ADs is beneficial and train primary care physicians, house staff, hospitalists, and oncologists to initiate these difficult discussions.

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INTRODUCTION

Advance care planning is the process by which patients, in conjunction with their health care providers and others close to them, establish preferences for medical care at the end of life. A critical aspect of this is completion of an advance directive (AD), a legal document allowing people to choose what they would want in the event that they lack capacity to make their own medical decisions. This may take the form of a living will or a durable power of attorney for health care. Only 20% to 40% of patients with cancer on inpatient oncology units have ADs completed on admission, a number that has not changed even with the passage of the Patient Self-Determination Act in 1992¹ and has remained relatively low despite evidence that having discussions

regarding ADs is an essential part of comprehensive care.² A growing number of people would like to be cared for at home, and AD discussions allow this wish to be communicated.³ Discussions early in cancer care are especially important, because delirium and other forms of cognitive impairment are prevalent during treatment for advancing malignancies.^{4,5} Absence of ADs may lead to unwanted aggressive care once patients have lost decision-making capacity,⁶ and this unwanted care has been associated with worse quality of life and quality of care for patients, as well as worse quality of life and bereavement adjustment for caregivers.^{6,7}

Hesitance to discuss end-of-life issues has been attributed to both patient and physician ambivalence.⁸⁻¹³ A decade ago, Lamont and Siegler¹⁴ found that patients with cancer would not like to

discuss these issues with their oncologist but, paradoxically, would endorse a policy of discussing them with the admitting physician, whom they had never met before. They found that 69% of patients had discussed their advance care preferences with someone, usually a family member, and 33% had completed at least one formal AD. However, only 9% of patients reported having discussed their advance care preferences with their clinic oncologists, and only 23% of the remaining patients stated that they wished to do so. By contrast, 58% of patients supported a policy in which medical house staff would offer to discuss these advance care preferences as a part of the admission history.

This study has been interpreted as showing that patients do not want to discuss ADs with their oncologists. However, this study assessed whether patients endorsed a policy in which the admitting physician initiates this conversation, not with which of their physicians they would choose to discuss ADs. In addition, it was not known whether there was correlation between ADs and knowledge of supportive care options (eg, hospice, palliative care) or ethnicity.¹⁵ African American patients in earlier surveys perceived that signing an AD would cause them to receive inferior care and be treated differently, and an Institute of Medicine report suggested further research focusing on understanding the reasons for differing attitudes regarding end-of-life practices and preferences for vulnerable populations.^{16,17}

The primary aim of this study was to readdress Lamont's original paradoxes and assess their steadfastness 10 years later in a different patient population. Secondly, we sought to determine with which of their physicians patients preferred to discuss ADs. Finally, we sought to evaluate differences between awareness of hospice/palliative care and preferences for AD communication according to patient attributes. This study was done to examine both the complexity of getting ADs (which most doctors and patients in this situation would agree are reasonable to have, given the severity of illness) and the paradoxes in communication preferences.

PATIENTS AND METHODS

Design

Semi-structured interviews were verbally administered in person with patients with cancer consecutively admitted to the hematology-oncology inpatient service at an urban academic medical center. Information was collected regarding ADs as well as knowledge of hospice and palliative care. The study was approved by the institutional review board.

Patients

Of 117 consecutive patients with cancer admitted to the Virginia Commonwealth University Medical Center Hematology-Oncology inpatient service between October 22, 2008, and January 23, 2009, 85 (73%) were offered entry onto this study. Of the 32 patients who were not offered entry onto the study, eight were discharged or transferred before they could be screened for eligibility, and 14 were not alert or they did not speak English. Eighty-eight percent (75 of 85) of eligible patients consented to the interview; the 10 who refused did not substantially differ with respect to demographics and disease traits from those who consented, leaving an analytic sample of 75.

Demographic data were collected from all patients. Data related to their disease process were collected from their medical record and included diagnosis, disease stage, and reason for admission. Patients were assured that their responses would not be shared with their oncologists.

Data Collection

The semi-structured interview instrument developed for the study included questions from Lamont and Siegler's original study, assessing patient

AD practices as well as their willingness to discuss them. Questions were added to assess patients' preferences regarding with which of their physicians they preferred to discuss ADs and to assess patients' awareness of hospice and palliative care. The instrument was administered to all consenting participants by one of the investigators (L.A.D.), a medical student completing a year-out master's program. Responses to the questions were recorded by the interviewer without any attempt to influence patients' decisions.

Statistical Analysis

We hypothesized that the rate of AD completion by patients would remain low at 33% and that the rate of patients who have discussed AD issues with someone would remain the same at approximately 69%. A sample size of 75, using an exact binomial test with a nominal 0.050 two-sided significance level would have 82% power to detect the difference between the historical rate of AD completion of 33% and an alternative rate of 50%. This sample size would also enable us to detect a difference between the historical rate of having had a discussion about ADs of 69% and an alternative rate of 83%.

Descriptive analyses were tabulated first for the sample as a whole and then for different subgroups based on demographics, disease characteristics, and awareness of supportive care options. Subgroup responses were compared using a χ^2 test. Multivariate analysis of selected yes/no questions was performed using a logistic regression model.

RESULTS

Respondents

The mean age of respondents was 51 years (range, 19 to 85 years), 51% (38 of 75) were female, 52% (39 of 75) were married, 69% (52 of 75) were white, and 23% (17 of 75) were African American. The most frequent cancer diagnoses were acute leukemia (44%; 33 of 75), non-Hodgkin's lymphoma (15%; 11 of 75), chronic leukemia (5%; four of 75), multiple myeloma (5%; four of 75), and breast cancer (5%; four of 75). In terms of admitting diagnosis, 41% (31 of 75) were admitted for elective chemotherapy (typically consolidation chemotherapy for acute leukemia) while 59% (44 of 75) were admitted for acute medical problems. Only 21% (16 of 75) had new diagnoses established during the current admission, and 79% (59 of 75) had chronic recurring serious conditions (Table 1).

Knowledge of Hospice and Palliative Care

Of the 75 patients interviewed, 81% (61 of 75) had heard of the term "hospice care," and 51% (38 of 75) knew of someone who had received hospice care. Only 53% (9 of 17) of African Americans were aware of hospice care versus 92% (48 of 52) of white patients ($P < .001$). Also of note, 100% (19 of 19) of patients older than age 65 years were aware of hospice care. Forty percent (30 of 75) knew someone who had received home hospice care, 11% (8 of 75) knew someone who received nursing home hospice care, and 13% (10 of 75) knew someone who had stayed in a hospice facility. Twenty-one percent (16 of 75) of the patients reported knowledge of palliative care, and 6% (5 of 75) said they knew someone who had received palliative care.

AD Knowledge, Practices, and Preferences

Thirty-seven percent (28 of 75) reported knowing what an AD was on commencement of the questionnaire. Seventy-one percent (20 of 28) accurately defined an AD and acknowledged its purpose in providing their wishes when they are unable to do so; six of the remaining eight patients inaccurately defined an AD as a do-not-resuscitate order. After being given a uniform definition of AD,

Table 1. Patient Demographic and Disease Characteristics (N = 75)

Characteristic	No. of Patients	%
Age, years		
Mean	51	
Range	19-85	
< 25	3	4
25-34	16	21
35-44	7	9
45-54	10	13
55-64	20	27
> 65	19	25
Sex		
Male	37	49
Female	38	51
Marital status		
Married	39	52
Committed relationship	8	11
Divorced	13	17
Widowed	6	8
Single/never married	9	12
Ethnicity		
White	52	69
African American	17	23
Asian	1	1
Hispanic	1	1
Multiracial	2	3
Other	2	3
Education completed		
Less than high school	5	7
Some high school	4	5
High school diploma/GED	25	33
Some college	20	27
Completed college	9	12
Some post-graduate	2	3
Completed post-graduate	10	13
Total household income, \$		
< 15,000	16	21
15,000-34,999	13	17
35,000-74,999	16	21
> 75,000	19	25
Don't know	4	5
Chose not to answer	7	9
Admitting diagnosis		
Elective chemotherapy	31	41
Acute medical problem	44	59
Cancer diagnosis made on current admission		
Yes	16	21
No	59	79

Abbreviation: GED, General Equivalency Diploma.

41% (31 of 75) reported having completed an AD, which does not differ significantly from the 33% found in the original study ($P = .132$). Notably, in the bivariate analyses, 50% (26 of 52) of white patients compared with 18% (3 of 17) of African American patients had completed ADs ($P = .041$). Those who had completed ADs were, on average, 14.5 years older (range, 26 to 85 years) than those who had not ($P < .001$). In a multivariate logistic regression model that controlled for patient and disease variables (sex, marital status, ethnicity, age, education, income, presumed treatment intent, new diagnosis, and knowledge of hospice and palliative care),

older age remained the only significant predictor (positive) of AD completion. Table 2 lists the odds ratios associated with each predictive factor.

Seventy-five percent (57 of 75) had previous discussions about ADs, which did not differ significantly from the 69% found in the original study ($P = .266$). Of those who had discussions, 77% (43 of 56) were with family members, and 41% (23 of 56) were with a physician. Of those who had a discussion regarding ADs with their physician, only 22% (five of 23) were with their medical oncologist, and in only two instances, the oncologist initiated the discussion. Of those patients age 55 years and older, 87% (34 of 39) had discussed ADs before, whereas only 61% (22 of 36) of those younger than age 55 years had previous discussions ($P = .010$). Of those with awareness of hospice services, 80% (49 of 61) had a previous discussion compared with 50% (seven of 14) of those with no awareness ($P = .019$). Similar to patient age in the previous multivariate logistic regression model, patient age 55 years or older was the only significant predictor (positive) of previous AD discussion.

Twenty-four percent (18 of 75) denied both completing an AD and ever discussing ADs with another person. Of those younger than age 55 years, 36% (13 of 36) had never documented or discussed their AD preferences compared with 13% (five of 39) of those age 55 years and older ($P = .018$). In the multivariate logistic regression model, younger age was the only significant predictor (positive) of no prior AD completion or discussion.

Of the 70 patients who had not previously discussed ADs with their medical oncologist, only 23% (16 of 70) reported that they would like to do so (the wording from the original survey). In the multivariate logistic regression model, there were no significant predictors that correlated with the desire to discuss ADs with their medical oncologist. The 54 patients who answered this question negatively were also asked an open-ended question regarding their response. Of the 54 responses, three major themes were noted: 28% (15 of 75) felt that an AD discussion was not yet necessary, 26% (14 of 75) felt that there would be no added benefit from this discussion, 22% (12 of 75) felt that it was more of a family or personal decision, and 19% (10 of 75) gave no particular reason. Three participants had responses other than those listed above, two stating that they did not want to discuss ADs but would if asked, and the other noting insufficient appointment time.

Of 75 patients, 87% (65 of 75) supported a policy in which admitting physicians offer to have a conversation regarding ADs as part of the hospital admission process. Of these patients, 95% (62 of 65) felt that it was either very important (46%; 30 of 65) or somewhat important (49%; 32 of 65) for ADs to be addressed at the beginning of the hospitalization. Of the patients who said they would not like to discuss their AD preferences with their medical oncologists, 87% (47 of 54) supported a policy in which their admitting physician offered to have such a conversation as part of the admission process.

Physician Preference of Patients

When directly asked with whom they would prefer to discuss ADs, 48% (36 of 75) chose their medical oncologist, 34% (26 of 75) chose their primary care physician, 11% (eight of 75) chose the admitting physician at the hospital, 3% (two of 75) chose their surgeon, 3% (two of 75) were undecided, and 1% (one of 75) preferred not to discuss ADs with any of their physicians. Table 2 illustrates patients' preferences for the type of physician they would want to discuss their

Table 2. Multivariate Association Between Patient and Disease Characteristics and AD Practices and Preferences

AD Practice/Preference	Odds Ratio	95% CI	P
Has AD			
Sex	0.54	0.143 to 2.053	.367
Marital status	1.09	0.680 to 1.733	.731
Race/ethnicity	1.11	0.558 to 2.198	.770
Age	2.29	1.395 to 3.749	.001
Education	1.36	0.875 to 2.121	.171
Income	1.00	0.980 to 1.016	.833
Treatment intent	1.00	0.977 to 1.014	.653
New diagnosis	0.71	0.150 to 3.392	.670
Knowledge of hospice care	0.19	0.031 to 1.142	.069
Knowledge of palliative care	3.04	0.634 to 14.541	.165
No AD and no prior AD discussion			
Sex	0.82	0.221 to 3.056	.770
Marital status	1.23	0.734 to 1.937	.477
Race/ethnicity	1.31	0.668 to 2.615	.423
Age	0.62	0.404 to 0.896	.012
Education	1.06	0.626 to 1.595	.997
Income	1.00	0.986 to 1.022	.681
Treatment intent	1.00	0.981 to 1.021	.943
New diagnosis	1.11	0.251 to 4.980	.885
Knowledge of hospice care	0.52	0.118 to 2.336	.397
Knowledge of palliative care	0.65	0.095 to 3.690	.574
Wants to discuss AD with oncologist			
Sex	0.56	0.141 to 2.243	.415
Marital status	1.37	0.817 to 2.299	.232
Race/ethnicity	1.26	0.612 to 2.577	.535
Age	0.78	0.526 to 1.157	.217
Education	1.48	0.884 to 2.468	.137
Income	1.01	0.991 to 1.027	.332
Treatment intent	1.01	0.990 to 1.027	.362
New diagnosis	0.34	0.055 to 2.071	.240
Knowledge of hospice	1.20	0.230 to 6.272	.829
Knowledge of palliative care	1.23	0.223 to 6.811	.811

Abbreviation: AD, advance directive.

ADs with if required to versus their actual practice regarding this matter. We asked all 75 participants an open-ended question regarding their reason for choosing a particular physician, and the responses fell into four major themes: 24% (18 of 75) felt that this was the physician who knew them best, another 24% (18 of 75) felt that this physician would be the most convenient or the one they would be interacting with the most, 21% (16 of 75) felt that this physician would be the most knowledgeable about how their disease would progress, and 16% (12 of 75) felt that this physician was the most personable. Nine percent (seven of 75) did not have a reason, and 5% (four of 75) gave other responses (Table 3).

DISCUSSION

A decade later, Lamont and Siegler's¹⁴ original paradox—that while most patients were willing to discuss ADs with a physician they had never met (ie, the admitting physician), they would not like to discuss them with their oncologist—still holds true. Similar numbers of patients have completed ADs, similar numbers of patients have had discussions regarding ADs, and similar numbers of patients would not like to discuss this issue with their oncologist. In addition, 87% of patients support a policy wherein admitting physicians have this con-

versation at the beginning of the hospital admissions process, and 95% thought that discussing AD issues was very or somewhat important. We have found an additional paradox—that while most patients would not like to discuss ADs with their oncologist, they would prefer to discuss them with their oncologist.

This goes against the interpretation that patients with cancer generally deem their admitting physician to be more important in

Table 3. Patients' Preferred Physician for AD Discussion v Actual Practice

Preferred Physician	Preference		Practice	
	No. of Patients	%	No. of Patients	%
Primary care physician	26	35	1	1
Admitting physician	8	11	14	18
Surgeon	2	3	1	1
Medical oncologist	36	48	5	7
Neither	1	1	52	69
I don't know	2	3	2	3
Total	75	100	75	100

Abbreviation: AD, advance directive.

AD discussions, or that they would prefer to discuss ADs with an anonymous physician. Studies show that patients feel these discussions should occur earlier than their physicians do, and that physicians should initiate them.¹⁸ An explanation for the incongruent results we obtained could be that while patients would not like to discuss this issue with their oncologist, they would be willing to do so if their admitting physician brought it up and would prefer to do so with their oncologist or primary care physician, because they find this issue important. They are just waiting for physicians to take the first step.

Several disparities were suggested by the data collected in this study. African American patients were both less aware of hospice care (53% v 92%) and had lower AD completion rates (18% v 50%) compared with non-Hispanic white patients. When multivariate analysis was performed, race by itself was not associated with AD completion, though numbers were too small to fully comment on. Not surprisingly, there were age-related differences in the responses to many questions. All patients older than age 65 years had heard of hospice care, and those who had completed ADs were generally older than those who had not. The older patients were also more likely to have engaged in discussions of ADs in general. Younger patients generally held the idea that these forms were not necessary yet.

There are some limitations to this study. The relatively small sample size and low patient diversity made it difficult to draw conclusions on the disparities observed but suggest a need for future research. A large number of patients had a diagnosis of acute leukemia instead of solid tumors, which may limit generalizability; however, these patients were admitted for complications or consolidation chemotherapy, and the majority will not be cured, so ADs are appropriate. In addition, our study was performed at an urban-academic tertiary care center, which may differ in both patient and physician qualities from the more common community setting. Additionally, we did not study patient feelings as part of this research, so we cannot demonstrate any findings. Another limitation is that we did not address the physician side of ADs in this study. Previous research in similar settings has shown that only 11% of physicians reported speaking to their imminently dying patients about impending death, but that those who did reported better satisfaction with end-of-life care practices.¹⁹ Recognition of the varying skills and types of oncologists (those with only a biomedical approach and those who incorporated a psychosocial approach) may help target interventions that avoid physician burnout and increase communication.²⁰

In conclusion, nearly all hospitalized patients with cancer think it is important to have discussions about ADs, are willing to have them with their doctors, and prefer their oncologists, but their oncologists do not initiate the discussion. Many have an AD discussion with a family member, but this does not always translate into completed documents that are communicated to their physi-

cians. We suggest that primary care physicians, house staff, hospitalists, and oncologists need to be better trained to have these difficult discussions. Residents rate both the quantity and quality of their end-of-life care education, including how to conduct an AD discussion, lower than the rest of their medical education, and often the information they give hospitalized patients regarding ADs is insufficient for them to make an informed decision.²¹⁻²³ Lack of time is not an excuse; in a study of 56 physicians,²⁴ the median AD conversation lasted 5.6 minutes, and in patient follow-up, 96% felt it was worthwhile; a similar inpatient study showed that most AD discussions took less than 16 minutes.²⁵ However, physicians are not the only ones who should be educated on the importance of documenting ADs; patients must also learn to communicate their wishes. While the idea that many patients feel this is a family or personal issue must be respected, this denotes only partial understanding of the concept of an AD. As physicians, we can dispel the myth that ADs are associated with impending death; in fact, those undergoing high-dose chemotherapy and stem-cell transplantation with an AD in place had two-fold better survival than those who did not have ADs.²⁶ We can also teach that patients who had AD or end-of-life discussions with their doctor had better quality of care with less resuscitation, ventilation, death in an intensive care unit, more and longer hospice use, and better caregiver quality of life.⁷ These discussions and better quality of care were also associated with significant cost savings to society.²⁷ These findings have encouraged us to look into innovative ways of educating house staff, patients, and practicing oncologists regarding earlier and higher quality communication regarding ADs.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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